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Article

Diabetic Retinopathy Screening Programme: Attendance, Barriers and Enablers amongst Young People with Diabetes Mellitus Aged 12–26 Years

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Abstract: The study aim is to investigate characteristics, barriers and enablers for attendance at the Diabetic Eye Screening Programme Northern Ireland (DESPNI) among people with diabetes aged 12–26 years. A mixed-methods approach with retrospective analysis and prospective, questionnaire-based data collection was completed. Data were analysed using ordinal logistic regression. A questionnaire collected information on barriers and enablers to attending DESPNI. Age, diabetes duration, attendance at diabetes clinic and lower HbA1c values were significantly associated with better attendance. Those aged 12–15 were more likely to attend screening than 16–26 years, odds ratio (OR) 4.01. Subjects diagnosed less than 5 years were more likely to attend than those with longer diabetes duration (OR = 2.52, $p < 0.001$). Subjects who attended diabetes clinics were more likely to attend screening (OR = 1.89, $p < 0.001$) and have a lower HbA1c (OR = 1.46, $p < 0.001$). Questionnaires revealed major barriers to attendance which included inconvenient appointment times, lack of access and poor communication. While many subjects were aware of the impact of diabetes on the eye, many had little understanding of screening. This study provides pivotal information on potential barriers and enablers for young people attending eye screening. We suggest modest changes such as convenient appointment times, clearer communication and one-stop clinics could improve attendance.

Keywords: diabetic retinopathy; diabetic eye screening; diabetes; young people

1. Introduction

Among the 1.87 million people living in Northern Ireland (NI), approximately 112,000 have diabetes mellitus, an increase of 62% in 10 years [1]. Approximately 2350 are young people aged 12–26 years.

One of most common microvascular complications of diabetes is diabetic retinopathy (DR). DR often leads to vision impairment and blindness although, early detection through diabetic eye screening programmes (DESPs) and timely treatment has been shown to be effective at preventing sight loss. Since the implementation of DESPs in the UK, DR is no longer the leading cause of blindness among working-age populations [2,3] and an estimated 400 diabetes-related cases of blindness are prevented annually [4].

A Diabetic Eye Screening Programme (DESP) in NI was established in 2008 offering annual eye screening services to individuals with diabetes. The programme aims to 'detect diabetic eye disease at an early stage and prevent sight loss in those with diabetes aged

12 years and over in NI'. It is a regional system, which is commissioned, and quality assured by the Public Health Agency and is delivered by the Belfast Health and Social Care Trust.

Transition clinics in diabetes care are designed to prepare young people with diabetes for the transfer to adult services by the age of 26. The process is multifaceted and involves three main phases: (1) introduction to the concept of transition provided by the paediatric team, (2) readiness for transition and preparation to begin, continue and finish the transition process and, (3) transfer to adult care and active participation in the adult services by the age of 26.

Good compliance with annual DESP appointments is essential as non-attendance is described as the greatest risk-factor for diabetes related blindness [5]. DR is a progressive disease with the risk of severe disease and sight loss related to duration of diabetes. Hence, it is especially important for children and young people to establish good patterns of attendance early in life in order to minimise risk of sight loss later in life [6]. Despite this, several studies suggest that non-attendance is highest in children and young adults with only 50–68% attending DESPs in the UK [7–9], a phenomenon described as 'teens falling off the radar' [8]. This result resonated with a pilot study in NI where attendance rates in this age group during 2016/17 were 73.8% for 12–17 years old and only 51.8% in those aged 18–30 [10]. Previous studies from the UK and Europe have reported that potential barriers to non-attendance at DESP in both young adults and adults include lack of awareness, fear, duration of disease, deprivation, working age group and transport and access issues [2,3,5,6,8,9,11,12].

This study seeks to investigate attendance rates at DESPs in NI among young people aged 12–26, and identify any barriers and enablers of attendance.

2. Materials and Methods

Ethical approval was obtained through the Health and Social Care Integrated Research Application System (IRAS) pathway and was given favorable opinion on 13 June 2019, reference number 19/NI/0112. The project was sponsored by the Belfast Trust.

This is a mixed methods study, including a retrospective analysis of 2330 records and a prospective, questionnaire-based data collection. Data for retrospective analysis were collected from the NI DESP database that covers the whole of NI as a single unified DESP. To determine the barriers and enablers to attending DESP, qualitative data were collected using semi-structured questionnaires. The questionnaire comprised 23 questions with a mixture of closed and open-ended questions covering age at diagnosis, gender, diabetes clinic attendance and finally barriers and enablers of attendance at DESP.

Questionnaires were distributed through diabetes clinics by letters with a Quick Response (QR) code and link to an online anonymous survey through the SurveyMonkey (Survey Monkey Inc., San Mateo, CA, USA) platform.

The DESP database (OptoMize) was used to ascertain the number of young people aged 12–26 in NI with a diagnosis of diabetes. This allowed the compilation of a list of 2370 young people with diabetes whose results were analysed retrospectively. Anonymised data were collected from the OptoMize system alongside the NI Electronic Care Record (ECR) and the NI Patient Administrative System (PAS). Data were collected between 10 June 2019 and 10 October 2019. Data were excluded for 25 individuals due to duplicates, change in marital surname and the individuals being deceased leaving 2330 subjects for analysis. Records were used to collect variables including age at time of data collection, gender, maculopathy and retinopathy grade (using the United Kingdom (UK) DESP grading system). Retinopathy and maculopathy grades were taken from the OptoMize system and the most recent grade on the database was used. In addition, individuals' postcodes were used to ascertain the deprivation score for each person. The Northern Ireland Multiple Deprivation Measure (NIMDM2017) ranks small areas in Northern Ireland in the order of most deprived (0) and least deprived (890) according to 7 domains including Income Deprivation, Employment Deprivation, Health Deprivation and Disabil-

ity, Education, Skills and Training Deprivation, Access to Services, Living Environment and Crime and Disorder. Self-reported smoking status was also collected following inquiry by the screener/grader. Date of diabetes diagnosis was provided by the General Practitioner (GP), however this was not always reported on registration. Diabetes clinic attendance, type of diabetes and HbA1c value were determined using the NI Electronic Care Record through clinic letters, clinical attendance and diabetes pathways. Attendance at DESP was recorded from the Optomize system, if someone attended, did not attend or was invited to an appointment it is recorded on the system. Attendance at DESP is coded as attended, did not attend appointment (DNA) and did not respond to invitation (DNRI). For further analysis, attendance was categorized as good (0 DNAs and DNRI), moderate (1–3 DNA/DNRI), and poor (more than 4 DNA/DNRI) (Table 1) engagement. For the purposes of this study engagement was defined as any contact with the young person including sending appointment letters, attendance at appointments and cancellation of appointments.

Table 1. Characteristics of patients attending Diabetic Eye Screening Service stratified by engagement index ($n = 1831$).

Characteristics Engagement (%)		Total 1831 (100)	Good 720 (39.3)	Moderate 804 (43.9)	Poor 307 (16.8)
Age, n (%)	Under 15	387 (21.1)	269 (37.4)	103 (12.8)	15 (4.89)
	16–19	489 (26.7)	162 (22.5)	228 (28.4)	99 (32.25)
	20–22	417 (22.8)	122 (16.9)	215 (26.7)	80 (26.06)
	23–26	538 (29.4)	167 (23.2)	258 (32.1)	113 (36.8)
Gender, n (%)	Male	974 (53.2)	379 (52.6)	442 (55.0)	153 (49.8)
	Female	857 (46.8)	341 (47.4)	362 (45.0)	154 (50.2)
Type of Diabetes, n (%)	Type 1	1796 (98.09)	705 (97.92)	788 (98.0)	303 (98.7)
	Type 2	35 (1.91)	15 (2.08)	16 (2.00)	4 (1.30)
Smoking Status, n (%)	Non-Smoker	834 (45.55)	342 (47.5)	371 (46.1)	121 (39.4)
	Smoker+ Ex	180 (9.83)	56 (7.78)	84 (10.5)	40 (13.0)
	Unknown/ Undefined	817 (44.62)	322 (44.7)	349 (43.4)	146 (47.6)
Worst eye grade, n (%)	R0	1293 (70.6)	573 (79.58)	537 (66.8)	183 (59.61)
	R1	482 (26.3)	138 (19.17)	234 (29.1)	110 (35.83)
	R2+	56 (3.10)	9 (1.25)	33 (4.10)	14 (4.56)
Maculopathy, n (%)	Yes	66 (3.60)	16 (2.20)	30 (3.73)	20 (6.51)
	No	1765 (96.4)	704 (97.8)	774 (96.27)	287 (93.5)
Deprivation Score	Mean (SD)	456.01 (246.43)	454.75 (242.19)	466.06 (250.80)	432.61 (243.87)
Diabetic Clinic Attendance n (%)	Yes	1524 (83.2)	642 (89.2)	659 (82.0)	223 (72.6)
	Frequently DNA	307 (16.8)	78 (10.8)	145 (18.0)	84 (27.4)
Diabetes Duration, n (%)	5 yrs & Less	285 (15.6)	201 (27.9)	74 (9.20)	10 (3.26)
	5–10 yrs	177 (9.67)	88 (12.2)	72 (8.96)	17 (5.54)
	10+ yrs	249 (13.6)	92 (12.8)	126 (15.7)	31 (10.1)
	Unknown/ Undefined	1120 (61.2)	339 (47.1)	532 (66.2)	249 (81.1)
HbA1c	Median (IQR)	68 mmol/mol (58.5–83)	66 mmol/mol (57–79)	69 mmol/mol (59–85.3)	73 mmol/mol (61–89)

Abbreviations: Fx DNA = frequently does not attend (appointments).

Data of 2330 individuals were entered into a Microsoft Excel (Version 2102) database; 499 participants with missing information of maculopathy, worst eye DR grade, diabetes clinic attendance and HbA1c, deprivation score were excluded from analysis. The demographics of the participants who were removed are as follows: Male 288 (57.7%), female 211 (42.3%), age range 12–26 with an age mean of 20.9 (SD-4, median—22, IQR 19–24), Type 1 diabetes 472 (94.6%) and Type 2 diabetes 27 (5.41%). Comparison between included and excluded cases showed that there was no statistically significant difference between groups for gender. A statistically significant difference in age was found between included and excluded cases (19.5 versus 20.9 years, respectively), however the difference of 1.4 years is unlikely to be clinically relevant.

Statistical Analysis

Demographics and characteristics of participants attending DESP stratified by engagement index were analysed. Categorical and continuous variables were presented as frequency (percentage), mean (standard deviation [SD]) or median (interquartile range) accordingly. The proportions of engagements levels defined as good, moderate and poor were calculated (Table 1). Brant's tests and Variance Inflation Factor (VIF) tests were performed to assess the parallel regression assumption and multi-collinearity of the data. Consequently, univariate and multivariate ordinal logistic regression analysis was performed to investigate the effects of the potential predictors on the level of patient engagement within the DESP service. Variables which were statistically significant ($p \leq 0.05$) in the univariate model were included in the final multivariate logistic regression model. All analyses were conducted using R (version 3.6.2, 12 December 2019, Platform: x86_64-w64-mingw32/x64, 64-bit)

3. Results

3.1. Quantitative Analysis

Demographic characteristics of study participants are described in Table 1. In total, 53.2% were female and 46.8% were male. The data collected were also spread evenly across age groups with 21.1% under 15 years old, 26.7% aged 16–19 years, 22.8% aged 20–22 years and 29.4% aged 23–26 years. A majority (98%) had a diagnosis of type 1 diabetes while 1.91% had type 2 diabetes. Data were obtained from young people across all of NI and the mean deprivation score was 456.01. Many young people (83.2%) regularly attended their diabetes clinics with the median HbA1c at 68mmol/mol (IQR 58.5–83). Many (70.6%) had no retinopathy and 26.3% had background retinopathy (R1). Only a small proportion (3.1%) had pre-proliferative retinopathy (R2) or greater and similarly, only 3.6% had maculopathy.

3.2. Univariate Analysis and Full Model

A number of variables were included in the univariate ordinal logistic regression model (see Table 2). Among all potential predictor variables analysed, age, smoking status, worst eye DR grade, maculopathy, diabetes clinic attendance, duration of diabetes (years) and HbA1c (Log2) were found to be statistically significant ($p \leq 0.05$) and therefore were included in the final model in the subsequent analysis.

Increasing age affects attendance at DESP in NI, younger people with diabetes (<15 years) were the most engaged. People with diabetes aged 16–19 years are less engaged than those aged 15 or under, with a decrease of 75.1% in their odds of engagement (odds ratio (OR) = 0.249). Diabetes duration also affects level of engagement to diabetic eye screening (DES). Those diagnosed most recently with diabetes (<5 years) were more likely to attend their screening appointments, odds of engagement was 2.52 times those diagnosed 5–10 years (OR = 2.52).

Attendance at diabetes clinics was a strong predictor for good engagement at DES appointments. Children and young people who attended their diabetes clinics were more likely to attend their eye screening appointments, odds of engagement for attendees increased 89% compared to non-attendees (OR = 1.89). Finally, HbA1c (on Log2 scale) was

statistically significant ($p \leq 0.05$) as for every one unit decrease in \log_2 HbA1c the odds of attendance increased by 46%.

Table 2. Logistic Regression Analysis—Univariate (all variables) and full model analysis (significant variables).

Characteristics	Univariate Analysis		Full Model	
	<i>p</i> -Value	OR (95% CI)	<i>p</i> -Value	OR (95% CI)
Age				
Under 15	Reference		Reference	
16–19	<0.001	0.206 (0.156, 0.271)	<0.001	0.249 (0.187, 0.332)
20–22	<0.001	0.190 (0.143, 0.251)	<0.001	0.249 (0.184, 0.335)
23–26	<0.001	0.191 (0.145, 0.249)	<0.001	0.245 (0.181, 0.330)
Gender - Male	0.797	1.023 (0.861, 1.22)	–	–
Diabetes Type - 1	0.495	0.805 (0.427, 1.50)	–	–
Smoking Status				
Non-smoker	Reference		Reference	
Smoker	0.00321	0.635 (0.469, 0.858)	0.561	0.908 (0.657, 1.26)
Unknown/Undefined	0.201	0.888 (0.741, 1.07)	0.473	0.931 (0.766, 1.13)
Worst Eye Grade				
R0	Reference		Reference	
R1	<0.001	0.521 (0.428, 0.635)	0.0794	0.818 (0.654, 1.02)
R2+	<0.001	0.362 (0.222, 0.588)	0.180	0.669 (0.372, 1.21)
Maculopathy - Yes	0.001	0.462 (0.291, 0.735)	0.843	0.946 (0.545, 1.64)
Diabetic Clinic Attendance - Yes	<0.001	2.17 (1.72, 2.73)	<0.001	1.89 (1.48, 2.42)
Diabetes duration				
5 years and under	Reference		Reference	
5–10 years	<0.001	0.413 (0.282, 0.602)	<0.001	0.396 (0.266, 0.589)
10+ years	<0.001	0.262 (0.186, 0.369)	<0.001	0.332 (0.230, 0.477)
Unknown/Undefined	<0.001	0.172 (0.13, 0.227)	<0.001	0.210 (0.155, 0.281)
Deprivation Score	0.524	1.0001 (0.9997, 1.0005)	–	–
HbA1c (\log_2)	<0.001	0.530 (0.423, 0.663)	0.00255	0.685 (0.535, 0.875)

3.3. Qualitative Analysis

Questionnaires were distributed by social media and through diabetes clinics in Northern Ireland. Participants were handed invitation letters with a QR code to access the survey. This questionnaire was distributed to many young people however only 25 people responded. Although this is a smaller sample size, data saturation of theme was reached.

Percentages from scaled questions in the questionnaire were grouped into quartiles (>25% minimally affects, 26–50%—some affect, 51–75%—moderately affects, 76+—strongly affects). Analysis was carried out using Braun and Clarke’s Thematic Framework Method and major themes were identified. These themes are described below.

Responses were collected from both genders (52% of respondents male) and across all age groups of 12–26 with more than half (56%) falling in the 16–20 years age group. The majority (84%) had been diagnosed between age 8–20 years (8–11 years—40%, 12–15 years—28%, 16–20 years—16%). Most (72%) were in full time education in a secondary/high school, with 4% enrolled in university and 24% in full time employment.

Hospital admission due to diabetes or diabetic ketoacidosis was reported by 52%. Most respondents (72%) used carb counting, blood monitoring and insulin injections as their primary management of diabetes with only five on insulin pumps.

Inquiry as to how diabetes affected their social lives showed an even spread among the quartiles: 24% minimally, 20% some, 20% moderate and 32% stating it strongly affects their social lives. In contrast, when respondents were asked whether their diabetes diagnosis created feelings of fear and anxiety, 44% stated it had minimal effect whereas 32% stated that it strongly affects, 8% and 12% stated it has some and moderate effect on their feelings of fear and anxiety, respectively.

Questions were asked on awareness of how diabetes could affect the eye. Most, 92%, had awareness, with 72%, having been informed by their endocrinologist. Eighty-eight percent were aware of the DESP in NI and stated they did attend their annual appointment. Despite this only 72% were aware they must attend both their annual DESP appointment as well as their community optometrist/optician on a regular basis, usually every 2 years.

Respondents were then asked to score their DESP NI experience from 0–100% (0 being not good and 100 being excellent), 44% scored the experience 100% with an additional 20% scoring above 75%, 16% scored it 50–75% with only 1 being below 50%. Seventy-six percent agreed that having their DESPNI appointment during their routine clinic attendance would be beneficial.

The questionnaire also allowed for open-ended answers. Data saturation was reached and no further themes were identified after 25 responses. The main barrier to DESP attendance was missing/getting time off work/school (11 responders). Others cited location of appointments, lack of communication about other times/days available and physical access to screening appointments/venues. Only one responder mentioned that they were fearful of what their results might be as they had not attended for a long time. Two responders felt that currently they had no barriers but recognised that this might change as they moved from school to further education/work.

When respondents were asked about potential enablers to attending screening, the most common theme was the time of appointments, with many ($n = 11$) wanting later appointment times. In addition, many wanted more education around the potential effect of diabetes on the eyes as they considered this would provide a stimulus for attendance. They also expressed a preference for information presented in an understandable manner as opposed to fear tactics. Some asked for online appointment booking facilities as well as online flyers as opposed to the current paper format. Respondents felt that DESPNI venues at the University or during their routine diabetes clinics would result in better attendance.

Respondents were asked about recommendations for improving access to DESPs. The majority gave no suggestions for improvements whereas some respondents wanted shorter appointment times. Others wished to be seen more than once a year, with quicker result times and greater availability to appointments. One respondent stated that there was a need for improved camera maintenance as on two occasions their appointment had been cancelled due to machine failure.

4. Discussion

Our study found that the main factors affecting children and young people's attendance at DESP are age, diabetes duration, routine attendance at diabetes clinics and HbA1c levels. A qualitative survey highlighted other factors including times of appointments, taking time off school and work and being aware of the importance of attending DESP annually.

Age was an important predictor as those under 15 years of age were more likely to attend than those above. This might be explained by greater parental involvement in children under 15. In addition once children reach 16 years or more, they gain more independence such as, opening their own hospital letters and starting to drive. Parents or guardians can be less involved in their child's daily diabetes management and perhaps do not bring them to their hospital appointments. In addition, they are at a point in life where

there is often an abundance of change, such as going to university, moving out and seeking full time employment/apprenticeships. As a consequence, self-management of diabetes may not always be a priority. There is however a scarcity of literature on this.

This study found that those with a shorter duration of diabetes were more likely to attend DESP. There are many reasons why those with longer duration might attend less frequently including complacency, or development of unrealistic optimism that they are not vulnerable to complications [13]. On the contrary, it might be due to denial or fear of finding out results as a participant in the study stated they were fearful of their results, especially if they had not attended appointments for a while.

Cetin et al., 2013 stated that raising awareness of DR is key in early diagnosis as well as timely treatment. Much of the literature shows that people are unaware of these facts and that many did not know that DR can be sight-threatening [8,14], a finding echoed by our study. In addition, many were not aware that DR is often asymptomatic until the final stages [5,15].

Further appropriate, informative and not merely frightening education was requested by many respondents. While Lake et al. in 2020 suggested that well-designed eye health and retinal screening leaflets might promote better attendance it was clear from our study that the young people wanted this in a digital format that is easily accessible and well designed [16]. The importance of attending both their annual DESP appointment and their high street optometrists needs to be emphasised [14].

This study showed that there was a link between attending routine diabetes appointments and attendance at screening. Therefore, while it is important that those with diabetes remain engaged with their diabetes care, the influence of diabetes clinics and the information gained there is paramount for understanding potential eye disease itself [8]. Assumptions should not be made that other health care personnel have delivered education about DR and the importance of DESP attendance. A multidisciplinary approach is required to target non-attenders in particular.

The finding of a relationship between lower HbA1c values and greater DESP engagement emphasizes the importance of holistic care and a multi-disciplinary team approach at routine diabetes clinics as this is where HbA1c measurement takes place. While there is minimal research into attendance rates at screening and HbA1c values, Luong et al. showed that children [17] with no retinopathy on average had lower mean HbA1cs than those with abnormal results. This is also consistent with other studies such as the ACCORD and DCCT studies [18,19].

In contrast with previous literature, deprivation was not found to be a significant factor in engagement with DESP in NI [14,20–22]. This was especially surprising as in the 2012 Necessities of Life Study it was determined that deprivation levels and financial hardship are more extensive in Northern Ireland as compared to the rest of the UK as a whole [23]. In NI, some of the most deprived areas are adjacent to the largest hospitals with diabetes services. In addition, some of the best schools are located in these deprived areas therefore young people are well educated. In addition, currently in NI, screening is completed in the individual's General Practitioner (GP) clinic/specific locations which is often close to the person's house or school and is easily accessible.

From the qualitative analysis it is clear that one of the biggest issues is inconvenient appointment times where the individual has to take time off work and school. Access to screening appointments (perhaps due to necessary accompaniment due to mydriasis) and lack of available appointment times by the screening programme were also deemed problematic. Some suggestions for improving this were later appointment times, online booking ability and appointments during routine diabetes appointments. In other findings, 52% self-reported admission to hospital due to diabetes or diabetic ketoacidosis (DKA). While this seems like a large proportion of people, it is unclear whether all admissions were due to DKA. There are no concrete numbers on admission due to DKA in Northern Ireland however reports from England and Wales suggest higher numbers of DKA admissions

post-transition [24]. Other literature suggests that 59% of DKA admissions are due to non-compliance and female teenagers have a higher risk [25].

Despite a large number of young people's data being available, smoking status and the date of diagnosis were missing in many cases, limiting some of the conclusions we can draw. In addition, the invitation to participate was designed with young people in mind. Despite the use of electronic access to the survey through a QR code scanned by their smartphone and being distributed for several months in clinic and online, there was a low response rate. This is likely to be indicative of the problem being researched. Many potential participants may not have been interested in helping with the survey or merely forgot to answer the survey. Perhaps some were put off by the fact it was about their diabetes or they were unsure of the diabetic eye screening programme.

5. Conclusions

This research provides pivotal information on screening for DR in children and young people in NI. These themes resonate not only with those in NI, but other findings in the literature as well. The sight of these young people might be better preserved if we continue to implement some modest changes such as more convenient appointment times, well designed and clear information on screening presented in a digital format and a multidisciplinary professional to equip them with the knowledge they need. In addition, longer GP opening hours including weekends to allow easier and more convenient screening times or mobile screening units in the most deprived areas could boost attendance at annual retinal screening.

Further in-depth research is needed into disengaged young people where the greatest problem may exist. Unfortunately making contact with this group to find out the true issues they face and how to address them is a major challenge.

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Data Availability Statement: Aggregate anonymous data are available on request from the corresponding author due to privacy and ethical restrictions. Single participant level data are not publicly available due ethical and privacy reasons due to patient data.

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References

1. Diabetes UK. Number of People with Diabetes in Northern Ireland Increases by 62.5% in a Decade. 2018. Available online: https://www.diabetes.org.uk/in_your_area/n_ireland/news/number-of-people-living-with-diabetes-jumps (accessed on 23 May 2021).
2. Kashim, R.M.; Newton, P.; Ojo, O. Diabetic Retinopathy Screening: A Systematic Review on Patients' Non-Attendance. *Int. J. Environ. Res. Public Health* **2018**, *15*, 157. [CrossRef] [PubMed]
3. Scanlon, P.H.; Stratton, I.M.; Leese, G.P.; Bachmann, M.O.; Land, M.; Jones, C.; Ferguson, B.; The Four Nations Diabetic Retinopathy Screening Study Group. Screening attendance, age group and diabetic retinopathy level at first screen. *Diabet. Med.* **2015**, *33*, 904–911. [CrossRef] [PubMed]
4. Scanlon, P.H. The English National Screening Programme for diabetic retinopathy 2003–2016. *Acta Diabetol.* **2017**, *54*, 515–525. [CrossRef] [PubMed]

5. Lewis, K. I wish someone had told me *Community Eye Health* **2011**, *24*, 10–11. [PubMed]
6. Harris, M.; Lacey, L. Ensuring the effective delivery of diabetic eye screening for children and young people in England. *Diabetes Care Child. Young People* **2014**, *3*, 59–63.
7. Gulliford, M.C.; Dodhia, H.; Chamley, M.; McCormick, K.; Mohamed, M.; Naithani, S.; Sivaprasad, S. Socio-economic and ethnic inequalities in diabetes retinal screening. *Diabet. Med.* **2010**, *27*, 282–288. [CrossRef] [PubMed]
8. Bone, H. Improving Diabetic Eye Screening Uptake in the Young. 2019. Available online: <https://phescreening.blog.gov.uk/2019/07/04/improving-diabetic-eye-screening-uptake-in-the-young/> (accessed on 25 May 2021).
9. Moreton, R.B.R.; Stratton, I.M.; Chave, S.J.; Lipinski, H.; Scanlon, P.H. Factors determining uptake of diabetic retinopathy screening in Oxfordshire. *Diabet. Med.* **2017**, *34*, 993–999. [CrossRef] [PubMed]
10. Public Health Agency and Belfast Health and Social Care Trust. Northern Ireland Diabetic Eye Screening Programme Annual Report 2016–2017. 2017. Available online: <https://www.publichealth.hscni.net/publications/diabetic-eye-screening-programme-annual-report-2016-2017> (accessed on 2 May 2021).
11. Lewis, K.; Patel, D.; Yorston, D.; Charteris, D. A Qualitative Study in the United Kingdom of Factors Influencing Attendance by Patients with Diabetes at Ophthalmic Outpatient Clinics. *Ophthalmic Epidemiol.* **2007**, *14*, 375–380. [CrossRef] [PubMed]
12. Çetin, E.N.; Zencir, M.; Fenkçi, S.; Akın, F.; Yıldırım, C. Assessment of awareness of diabetic retinopathy and utilization of eye care services among Turkish diabetic patients. *Prim. Care Diabetes* **2013**, *7*, 297–302. [CrossRef] [PubMed]
13. Lake, A.J.; Browne, J.L.; Rees, G.; Speight, J. What factors influence uptake of retinal screening among young adults with type 2 diabetes? A qualitative study informed by the theoretical domains framework. *J. Diabetes Complicat.* **2017**, *31*, 997–1006. [CrossRef] [PubMed]
14. Hipwell, A.E.; Sturt, J.; Lindenmeyer, A.; Stratton, I.; Gadsby, R.; O'Hare, P.; Scanlon, P.H. Attitudes, access and anguish: A qualitative interview study of staff and patients' experiences of diabetic retinopathy screening. *BMJ Open* **2014**, *4*, e005498. [CrossRef] [PubMed]
15. Lian, J.; McGhee, S.M.; Gangwani, R.A.; Lam, C.L.K.; Yap, M.; Wong, D.S.H. Awareness of diabetic retinopathy and its association with attendance for systematic screening at the public primary care setting: A cross-sectional study in Hong Kong. *BMJ Open* **2018**, *8*, e019989. [CrossRef] [PubMed]
16. Lake, A.J.; Hateley-Browne, J.L.; Rees, G.; Speight, J. Effect of a tailored leaflet to promote diabetic retinopathy screening among young adults with type 2 diabetes: A randomised controlled trial. *BMC Ophthalmol.* **2020**, *20*, 80. [CrossRef] [PubMed]
17. Luong, O.; Fox, H.; Jain, G.; Williams, R. G452(P) Diabetic eye screening: Keeping an eye on attendance. *Arch. Dis. Child.* **2016**, *101*, A268–A269. [CrossRef]
18. Sosnowski, C.; Janeczko-Sosnowska, E. The Action to Control Cardiovascular Risk in Diabetes Study Group. Effects of intensive glucose lowering in type 2 diabetes. *Kardiol. Pol.* **2008**, *66*, 1013–1019. [PubMed]
19. Nathan, D.M.; DCCT/Edic Research Group. The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study at 30 Years: Overview. *Diabetes Care* **2014**, *37*, 9–16. [CrossRef] [PubMed]
20. Lindenmeyer, A.; Sturt, J.A.; Hipwell, A.; Stratton, I.; Al-Athamneh, N.; Gadsby, R.; O'Hare, J.P.; Scanlon, P.H. Influence of primary care practices on patients' uptake of diabetic retinopathy screening: A qualitative case study. *Br. J. Gen. Pract.* **2014**, *64*, e484–e492. [CrossRef] [PubMed]
21. Millett, C.; Dodhia, H. Diabetes retinopathy screening: Audit of equity in participation and selected outcomes in South East London. *J. Med. Screen.* **2006**, *13*, 152–155. [CrossRef] [PubMed]
22. Scanlon, P.H.; Carter, S.C.; Foy, C.; Husband, R.F.A.; Abbas, J.; Bachmann, M.O. Diabetic retinopathy and socioeconomic deprivation in Gloucestershire. *J. Med. Screen.* **2008**, *15*, 118–121. [CrossRef] [PubMed]
23. Gordon, D.; Mack, J.; Lansley, S.; Main, G.; Nandy, S.; Patsios, D.; Pomati, M. The Impoverishment of the UK; PSE UK First Results: Living Standards. 2013. Available online: https://www.poverty.ac.uk/sites/default/files/attachments/The_Impoverishment_of_the_UK_PSE_UK_first_results_summary_report_March_28.pdf (accessed on 25 June 2021).
24. NHS Digital. National Diabetes Transition Audit, 2003–2014. 2017. Available online: https://files.digital.nhs.uk/pdf/g/m/report_v1.0.pdf (accessed on 8 May 2021).
25. Allan, B.; Sampson, M. Admissions Avoidance and Diabetes: Guidance for Clinical Commissioning Groups and Clinical Teams. 2013. Available online: <https://diabetes-resources-production.s3-eu-west-1.amazonaws.com/diabetes-storage/migration/pdf/admissions-avoidance-diabetes-0114.pdf> (accessed on 7 May 2021).